

NHII 04 – Personal Health Record Track

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Background Material

Breakout Coordinators:

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Invited experts:

- Wendy Angst
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I. Proposed Goal State

*From Charles Safran's 2003 summary of the Consumer Health Track:
"Individuals have the information, tools, services and incentives to
manage their own health and wellness throughout their lifetimes."*

*2003 Vision: "Persons are the center of a US 'virtual health system' that
optimally enables them to optimize their health."*

Proposal for 2004 PHR Track: "Throughout their lifetimes, all U.S. residents have full access to, and can manage to the extent they desire, all information related to their health and health care, from all sources of care and service. Consumers and health care professionals contribute to personal health records, and have trust in the information itself, confidence in its security, accuracy and completeness, and full use of it to successfully manage personal health, promote provider-patient collaboration and improve the safety and effectiveness of health services."

Critical Definitions

Personal health records

Personal Health Records (PHR) are individually-held and controlled life-long repositories of (1) all clinical encounters; (2) health promotion activities; (3) personally-valued health monitoring parameters such as exercise, nutrition and spiritual well being; (4) decision support, risk management and professional advice; (5) consumer-focused health information and education; (6) benefits and financial management resources and (7) environmental exposure and community health monitoring information.

To insure full utility of health information toward accomplishing health goals, the PHR must include content relevant to the health of the person and archival recordings of health care services. A well-designed PHR can be tied to health advisories, guidelines and best practice information, and educational materials as needed and appropriate. PHRs must also have a robust set of functions that support access control, interpretation of data, and insure privacy and confidentiality.

PHRs complement the *clinical records* generated and held by health care providers and institutions, and may serve as pointers to the information stored at selected health care institutions.

Clinical Records

Clinical Records represent the archival accounting of care services provided through formal health care providers and institutions.

Life-long health records

Life-long health records are the amalgam of health information, accumulated over an individual's lifetime, from all health care providers and incorporating the personal health monitoring data generated by the individual.

Functionality

The PHR is both a document repository and a set of critical functions. Essential functions include access to Clinical Records, management of personal records, and access control/privacy strategies.

PHRs should comply with all information, language, and message standards common to any health care information system.

II. Recommendations from NHII 03 (Consumer Track)

(see attached complete list)

The 2003 Summit addressed several dimensions of consumer health and made a number of wide-ranging recommendations. The 2004 Summit is only considering the role of the Personal Health Record in support of the NHII; for this reason we confine our attention to this subset of the 2003 consumer health recommendations:

- Standards should include data elements relevant to consumers and patients
- HHS should resolve patient identification issue
- NLM funds the development of reference terminology models, vocabularies and vocabulary management tools to support efficient access to clinical records and health information through consumer terminology
- HHS supports systems with diverse modules to address literacy/cultural variations
- HHS develops metrics to monitor progress in personal health dimension
- NLM and private sector offer tools to link PHR with relevant information
- Funders prioritize medication management projects that include patients
- CMS supports demonstration with "patient centered remote information services"
- AHRQ supports demonstration to educate consumers, patients and professionals about consumer health technology
- HHS encourages patient component in regional information networks
- NIH conducts initiative to improve communication between patients and providers
- A public/private partnership creates PHR systems and makes them freely available.

III. Progress since July 2003

The following represents the expert assessment of progress towards the goals identified above:

- Standards should include data elements relevant to consumers and patients
Modest progress; HL7 functional model addresses patient requirements and CCR has begun "PHR extension" process, but data standards activities do not yet reflect this work-in-progress. Few data standards exist to address health information supplied by the patient (e.g., symptom reports, health behaviors, care preferences). Work is underway to define a minimum data set for PHR.
- HHS should resolve patient identification issue
We are unaware of relevant activity by HHS. The Connecting for Health Digital Identity workgroup will release a paper in July 2004, which will recommend a federated model for the

local or regional construction of patient identifiers based on commonly available personal information.

- NLM funds consumer terminology
Selected groups, (e.g., Patrick at U Missouri) have proposed various strategies towards vocabulary development, including augmenting existing health care vocabularies with vernacular terms. No progress has been made in the development of vocabulary management tools that map between vernacular and formal terminologies. Work by NLM and the Healthwise Center for Information Therapy may provide additional resources.
- HHS supports systems with diverse modules to address literacy/cultural variations
We are not aware of focused HHS work beyond a January 2004 evidence review (<http://www.ahrq.gov/downloads/pub/evidence/pdf/literacy/contents.pdf>). There is also significant academic work at Harvard Public Health (Rudd) and Johns Hopkins (Roter). (<http://www.hsph.harvard.edu/healthliteracy/>)
- HHS develops metrics to monitor progress in personal health dimension
NCVHS was doing something along these lines in mid-2003.
- NLM and private sector offer tools to link PHR with relevant information
Several innovations at NLM and NCBI, like the 'local link out,' address this issue. Group Health Cooperative has embedded Healthwise links into the patient accessible EMR within the GHC patient Web portal (EpicCare's MyChart). WebMD's Health Record links all technical content to resources such as Medline plus, Multum, DHHS, and Healthwise. Palo Alto Medical Group's Epic MyChart and Beth Israel Deaconess Medical Center's PatientSite allow patients to see their test results online and link those results to explanatory information about them.
- Funders prioritize medication management projects that include patients
We are not aware of funder activity (AHRQ, NIH, CMS, RWJF, etc.) but there are a number of private sector initiatives that address patient requirements, including SOS Rx, EHI Incentives report, AARP WiseUse program, Walgreen's, MedcoHealth, and Surescripts programs. Of these, SOSRx is the most strongly associated with involvement of patient advocates in design.
- CMS supports demonstration with "patient centered remote information services"
We are unaware of CMS activity in this area. Private sector activity includes work within Intel and some of the Smart Home projects at Georgia Tech and at Rochester. {I thought the VA's Health-e-Vet program was doing some of this?}
- AHRQ supports demonstration to educate consumers, patients and professionals about consumer health technology
We are unaware of AHRQ activity; NLM has had outreach in this area.
- HHS encourages patient component in regional information networks
None of the first-round LHII projects include a significant patient component; some current NLM projects have this focus.
- NIH conducts initiative to improve communication between patients and providers
NCI has conducted research in this area. The RWJF e-health initiative program for 2004 focuses on evaluating provider-offered patient portals.
- A public/private partnership should create PHR systems and make them freely available.
We are unaware of such activity at present.

IV. Proposed recommendations for discussion

We advance two sets of recommendations: those that address policy and communication issues, and those that advocate for demonstrations.

- Policy and Communication Priorities
 - Develop a messaging and branding strategy to increase uniform public and professional understanding of PHR.
 - Conduct an aggressive effort to develop and implement a mechanism that permits accurate integration of an individual's complete health record (e.g., patient identification algorithm)
 - Insure consideration of consumer perspectives in regulation and implementation of personal health records through:
 - Consumer representation on NCVHS and other relevant bodies
 - Increased opportunities for consumers to present testimony to IT standards and policy bodies
 - *Note:* identification of consumers for these activities should occur in collaboration with selected consumer groups as well as through election of individuals known to be active participants and early adopters of PHRs.
 - Develop standard templates for selected health system transitions (building upon CCR activity)
 - Develop mechanisms for patient access to personal health records that ensure equitable access for all people across diverse platforms and in diverse environments, recognizing the wide range of technical knowledge and skills and information self-efficacy across the U.S. population.

- Demonstration projects

We envision four short-term opportunities and would ask the NHII Summit participants to debate and then recommend at least one for early adoption efforts:

1. Personal Medication List – a complete enumeration of all prescribed substances
 - a. There could be a good financial case made here, and with about 50% of adults on some kind of prescription medication this would make sense
 - b. Builds on Medicare Modernization Act implementation
 - c. Challenges in each arena: identifier, standards, access, HIPAA/legal, business model, evaluation criteria, interface to EMR, etc.
 - d. E-prescribing transaction conduits (e.g., Zix Corporation) and hubs (e.g., RxHub, SureScripts) have access to dispensed drug history information and could provide this to patients as they are doing for physicians linked to certain initiatives
2. Implement standard intake/history/health summary forms and visit records as common tools for use by all electronic health record applications:
 - a. CCR standard could provide model
 - b. May be difficult to stimulate general adoption
 - c. Adoption of a minimum data set, much like UHDSS, is necessary
3. Create community-wide demonstrations of PHRs within existing, successful LHIs
4. Conduct a pilot with CMS to establish a free PHR for every new Medicare beneficiary who receives an initial risk assessment and exam, per the Medicare Modernization Act.

"Relevant" recommendations from Jon Wald's section, 2003

(note that the Consumer Health Track was broader than 2004 PHR focus, so I've only referenced ones I thought relevant to 2004)

Data interoperability

- Standards should include data elements relevant to consumers and patients
- HHS should resolve patient identification issue

Electronic communication and data sharing

- NLM funds consumer terminology
- FCC encourages broadband to the home
- Define lowest common denominator platform for NHII access

Information management by consumer

- NCVHS includes consumer representatives
- HHS supports consumer health literacy training
- HHS supports systems with diverse modules to address literacy/cultural variations
- HHS develops metrics to monitor progress in personal health dimension

Relevant health information

- NLM and private sector offer tools to link PHR with relevant information

Patient safety

- Involve patients directly in AHRQ patient safety initiatives
- Funders prioritize medication management projects that include patients

Demonstration projects

- CMS supports demonstration with "patient centered remote information services"
- AHRQ supports demonstration to educate consumers, patients and professionals about consumer health technology

Consolidated research agenda

- HHS encourages patient component in regional information networks
- NIH conducts initiative to understand patient needs and preferences
- NIH conducts initiative to improve communication between patients and providers

Additional recommendations from Safran group:

- Public/private partnership creates "consumers union" that bridges to individual capabilities
- Public/private partnership creates PHR systems and make them freely available.